Huntington's NEWS
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Living With HD: Living Positively At-Risk for HD

Jang-Ho Cha, MD PhD, Chair Center Programs and Education Advisory Committee

Dr. Jang-Ho Cha is currently the Director of Clinical Research in Neuroscience at Merck & Co outside of Philadelphia, PA. USA

I am often asked by HD patients and their families about what the best way is to live.

I wish I knew for sure. This is a really tough question to answer, but here's what I know: At this point, there is no treatment or intervention that is know for sure to slow down or delay the progression of HD. As a result, there is nothing that I can tell people for sure that will be helpful.

On the other hand, there are reports about medications or nutritional supplements that might be helpful. Should one try to start taking these medications? Most of the time, **the answer is no**.

For example, a fairly typical occurrence is that there is a report that some scientist somewhere has administered a medication to HD mice with beneficial effects. "Should I start taking it?" For one, I think it is good news any time there is any progress, but one should be very careful about interpreting these kind of reports. For every report of benefit in an HD mouse, even more important questions are raised:

- Will this treatment work in people with HD?
- Will this treatment work in people who are at-risk for HD?
- Is this treatment safe for people with HD?
- Will this treatment be harmful for people with HD?
- What is the right dose?
- Have these results been duplicated by another lab?

These are important questions, and most of the time, the answer is "I don't know." By the way, these questions are so important that we would all like to know. Unfortunately, there are no quick answers for these important questions. It is exactly these kinds of questions that are addressed in clinical trials, and answering these important questions is **why participation in clinical trials is so important.**

So what are we to do in the meantime? For all experimental medications that do not have an adequate safety record, I strongly recommend **not taking these medications**. Even well-researched medications are eventually found to have serious, even deadly side effects, so I am reluctant to recommend any medication that hasn't been subjected to careful review by the Food and Drug Administration (FDA). I think that there is more experience for the nutritional supplements, creatine and coenzyme Q10, although still not approved by the FDA, and so I discuss these options with my patients. Importantly, the jury is still out on whether these nutritional supplements are really helpful or not.

Finally, I recommend not-medication approaches. I am a firm believer that **maintaining mental and physical activity is helpful for both HD patients and at-risk persons**. Part of my belief comes from working closely with HD patients; I think those patients who do more, do better, with appropriate limits for what they can handle.

In 2001, Anton van Dellen and Tony Hannan, both then at Oxford University in England, made an amazing observation regarding environmental enrichment. They did an experiment in

Continues on page two

Continued from page one

which one group of HD mice were housed in standard conditions and the other group was put into an enriched environment. For mice, this means a new toy in the cage every three days, and exercise wheel, and other mice. There were not medications given to the mice. Surprisingly, the 'enriched' mice showed better motor performance, delayed onset of symptoms, and slower progression. In 2010, collaborating, with these scientists, we published a paper in the journal of Neuropathology and Experimental Neurology that showed that the brains of enriched mice had much smaller amounts of the abnormal huntingtin protein deposits. These results told us that enriching the mice's environment seems to make their brain more resistant to the harmful effects of the mutant huntingtin protein. Read that sentence again. Using your brain makes it stronger.

So, maintaining mental and physical activity is not optional. By the way, this advice holds true for all of us, whether we come from HD families or not!

Acknowledgement: The Marker – Spring 2011

Living with HD:Decision-Making

for Reproduction in Individuals At-Risk for HD

by Kimberly A Quaid, PhD, HDSA Centre of Excellence at Indiana University

The Prospective Huntington At-Risk Observation Study (PHAROS) is a multi-site observational study that aims to establish whether experienced clinicians can reliably determine the earliest clinical symptoms of HD in a sample of 1001 individuals at 50% risk for Huntington's Disease (HD) who have chosen not to be tested. As part of the funding for the study, the NIH included money to conduct qualitative interviews with the subset of PHAROS participants. Interviewers were recruited from the research coordinators from the top PHAROS enrolment sites. Unstructured open-ended qualitative interviews were conducted on a subsample of 55 PHAROS participants at six PHAROS sites across the country: Atlanta GA, New York City, NY; Dublin, OH; Wichita, KS; Minneapolis, MN; and Indianapolis, IN.

Most of the literature on reproduction in those at-risk for HD has focused on the impact of genetic testing on reproductive decision-making. In our interviews, we sought to understand the reproductive decisions in those at-risk who had chosen not to be tested. After reading and re-reading our interview transcripts, we indentified three groups of participants:

1. Those who had children despite knowledge of their risk,
2. Those who did not know their risk prior to having children; and
3. Those who knew their risk and chose not to have children.

For those in Group 1 who know of their risk and decided to have children, we identified four main themes:

1. Hoping for a Cure,
2. Feeling Guilty,
3. Magical Thinking;
4. Just Another Something.

The theme "Hoping for a Cure" reflects the fact that several individuals in this group stated explicitly that their decision to have children was based on the hope for a cure in the near future. The idea was that by the time their children reached the age of onset of symptoms, there would be a cure available and they would not have to worry about developing HD. The second theme "Feeling Guilty" reflects the feelings of guilt expressed by some participants about the decision to have children despite their genetic risk. The third theme "Magical Thinking" embodies the stated belief, on the part of participants, that they simply would not get HD. The fourth theme "Just Another Something" was a direct quotation from one of our participants and reflects the desire on the part of our participants to live their lives as normally as possible while refusing to let the risk of HD influence their decision, including, the decision whether or not to have children.. From this perspective, HD was just one possible negative event in a long list of potential negative life events and should not be given any special attention when making life choices.

For Group 2, those who had children before they knew of their risk, we identified two major themes:

1. Too Little Too Late, and
2. Getting It Wrong.

The theme of "Too Little Too Late" reflects the fact that in this group, many lacked information about HD or the inheritance of HD prior to choosing to start a family.

The second theme "Getting It Wrong" characterizes the participants in this group who had information about HD, but whose information was either inaccurate or simply wrong. Thus, in this group, they made the choice to start a family without fully understanding the genetic aspects of HD and only later came to appreciate the fact that they

Continues on page three

Continued from page two

may have already passed on the genetic mutation that causes HD.

For the third group of participants, those who knew of their risk for HD and chose not to have children, we identified three main themes:

1. Vigilant Witness,
2. Stopping HD; and
3. Being Alone.

For the main theme "Vigilant Witness" participants shared poignant stories about witnessing the decline and death of family members due to HD. Many had been actual caregivers of sick relatives, often a parent, and most had witnessed the destructive forces of HD in several generations. In the second theme in this group, "Stopping HD," many had been told in no uncertain terms, and sometimes by their own family members, not to have children, and to stop the line of HD in their family. This advice was taken to heart. In the third theme, "Being Alone" participants described how they lived their lives avoiding intimate relationships, or denied themselves having children in order to avoid harm to others should they become ill. As a consequence of these choices, many voiced worry about the fact that if they were to become ill, there was no one to take care of them.

When predictive testing using linkage first became available in 1986, many health professionals, myself included, believed that one major use of the technology would be to allow individuals at-risk to determine whether or not they carried the HD gene and use further testing and reproductive technologies to prevent passing on the HD gene. We believed this because that was what we were told by individuals at-risk. However, the number of individuals at-risk choosing to be tested remains low; most requests for testing come after the at-risk individual has completed his or her family, and the number choosing prenatal testing is miniscule.

The decision whether or not to have a child is intensely personal under the best of circumstances. When there is a 50% chance to pass on an incurable genetic disorder, the decision becomes even more complicated. There are your hopes and wishes for the future, the experience of HD in your family, your fears of future illness, and the desires of your partner, all which need to be factored into an irrevocable choice. We did this study to shed light on some of the factors that go into making these decisions and hope we did so in a manner that is respectful of all choices that were made and adds to our understanding of the experience of being at-risk for HD.

Reference: Quaid KA, Swenson MM, Sims SL, Harrison JM, Moskowitz C, Stepanov N, Suter GW, and Westphal BJ for the Huntington Study Group PHAROS investigators and coordinators (2010) What were you thinkin?: Individuals at risk for Huntington Disease talk about having children. Journal of Genetic Counseling 19:606

Acknowledgement: The Marker – Spring 2011

- ***Huntington's disease research news***
- ***In plain language.***
- ***Written by scientists.***
- ***For the global HD community.***

What is HDBuzz?

HDBuzz is the first internet portal for the rapid dissemination of high-quality Huntington's disease (HD) research news to the global community, written in plain language, by HD clinicians and scientists. It covers laboratory and clinical research, with the aim of helping HD people to understand the latest HD science, on their own terms.

All content is disseminated from hdbuzz.net via free syndication to other HD community websites, blogs and social media platforms like Facebook and Twitter.

Who are you?

HDBuzz was founded by Dr Ed Wild and Dr Jeff Carroll, HD scientists in the UK and USA, respectively. We recruited a number of people to help — see the people page. Everyone involved is already active in the HD community, in various capacities.

Is HDBuzz impartial?

We hope so. We go to great lengths to be impartial in our reporting:

We don't accept funding from any drug company or organization with a vested interest in a particular treatment or technology.

No funding organization gets any editorial control over HDBuzz content. An oversight committee of independent clinicians, scientists and lay community members meets regularly to ensure our content is impartial, scientifically accurate and understandable. All our authors make financial disclosure statements, which they review whenever they contribute new content.

Please check out this excellent website @ http://hdbuzz.net/

Cut-and-paste DNA: fixing mutations with 'genome editing'

Scientists make precise changes to the DNA of a live animal. Could it work for human genetic diseases?

By Dr Jeff Carroll on July 18, 2011 Edited by Dr Ed Wild

What if we could edit the DNA of patients to remove the Huntington's disease mutation altogether? Sounds like science fiction, but new research in an animal model of haemophilia suggests that it can work — and now HD researchers are on the case.

DNA, RNA and protein

Genome editing uses special molecular scissors to cut DNA in cells at exact places. Then new DNA is spliced in at the cut site. Every case of Huntington's disease is caused by a DNA mutation. The DNA code is written in four 'letters' that scientists refer to as bases. The four bases are adenine, cytosine, guanine and thymine — abbreviated as A, C, G and T.

Normally, near one end of the huntingtin gene, there's a stretch of 17 or so repeated C-A-G bases. In people with HD, the normal C-A-G stretch is longer, due to a kind of genetic stutter. That's the 'triplet repeat expansion' that causes HD.

Genes are the blueprint for everything a cell does. They're spelled out in DNA. When a gene is switched on, first the cell makes a 'working copy' of the gene, by copying the DNA into a message molecule made from a chemical cousin, RNA.

These RNA message molecules are used to direct the construction of proteins from *amino acid* building blocks. In Huntington's disease, the damage is done by the mutant *huntingtin protein* — not the huntingtin gene (made from DNA), or the RNA message molecule.

Gene silencing — shooting the messenger

There is a lot of excitement about ***gene silencing***. In this approach to therapy, specially designed molecules find the HD gene's RNA message and tell the cell to get rid of it. The gene itself still exists in the DNA in every cell of the person, but because the message is destroyed, less mutant *huntingtin protein* is made.

Several different strategies are being tried to silence huntingtin RNA, including *antisense oligonucleotides* and *RNA interference*. You can read more in our *Gene Silencing* Primer.

The next frontier — *genome editing*?

Gene silencing is definitely one of the most important therapeutic approaches to Huntington's disease. But what if we could actually go one further and remove the mutation that causes HD from the DNA of patients?

The idea seemed completely impossible until recently. Cells have mechanisms that repair DNA if it's altered, and every cell in the body has the same DNA. So the idea is much more radical than *gene silencing*.

Recently, though, a technology called ***genome editing*** has been developed. This approach uses a custom-made molecular machine called a **zinc-finger nuclease** to actually edit the DNA of a cell.

The mice were cured of haemophilia by editing the genome of their liver cells to correct the defective gene.

Zinc-finger nucleases are molecules with two special components.

The zinc finger bit can recognize and stick to specific sequences of DNA. That allows the machine to find a very specific point in the DNA code. And that exact point can be specified by the scientist designing the molecule.

Once the zinc fingers have brought the machine to a specific place in the DNA, the second part of the machine — the 'nuclease' — is brought into action. This little machine makes precise cuts in both strands of the DNA.

Cells are evolved to hate breaks in DNA, because breaks can lead to harmful mutations. So whenever a break occurs, the cell's repair machinery kicks in to try to fix it.

Here's the really clever part. If a little bit of custom-made DNA is supplied along with the zinc finger nuclease, the cell's repair machinery can be 'hijacked' to replace the normal DNA at the site of the cut.

Genome editing allows scientists to consider something that's never been possible — actually altering the DNA of a cell, to end up with any sequence we can design. In essence, the zinc finger nucleases make a cut in the DNA, and a different DNA sequence can then be pasted in.

Continues on page five

Continued from page four

Correcting haemophilia with *genome editing*

Genome editing sounds all very well in a test tube, but could we actually use it to treat diseases?

Recent work from the group of Prof Katherine High at the University of Pennsylvania suggests that it **is** possible. She studies a disease called **Haemophilia**, which reduces the ability of the blood to clot. That's bad news because it can lead to dangerous, uncontrolled bleeding.

Haemophilia B in people is caused by mutations in the F9 gene. F9 is a critical component of the blood clotting mechanism. Mutations in the F9 gene are scattered across the gene — different people have mutations at different spots. That's very different from Huntington's disease, where every patient has a mutation in the same place.

People with haemophilia have blood that doesn't clot properly. Genome editing restored normal blood clotting in mice with the haemophilia mutation. High's team had a very clever idea for replacing defective F9 genes using *genome editing*. Working with a company called Sangamo BioSciences, they designed a zinc-finger nuclease to put a cut very early in the F9 gene. They then added a DNA template that included a normal copy of the F9 gene. When the template and the zinc-finger nuclease were put into cells, some of the cells ended up with normal F9 genes in their DNA. In effect, the scientists had precisely spliced a new F9 gene where the old mutant copy was.

But could this ever work in the complex setting of a live animal? Most clotting proteins are made in the liver, so for Haemophilia B patients the important thing to do is to repair the F9 gene in the liver.

High's team used genetically altered mice with a mutated human F9 gene in the liver. They then injected these mice with a virus carrying a cocktail of zinc-finger nuclease and a DNA template including a new, healthy copy of the F9 gene.

Amazingly, after being injected with these viruses, the protein corresponding to the healthy F9 gene was found in the blood of the mice.

That means the viruses worked: they inserted a new copy of the F9 gene to the liver of mice and the cells actually started using it.

Of course, the most important test for a therapy is whether it corrects symptoms of the disease it's meant to treat. Mice and humans with haemophilia B have very slow clotting times — which can lead to serious bleeding problems.

But in the mice treated with viruses carrying the *zinc-finger nucleases* and the healthy F9 gene, the problems in clotting time were almost completely corrected. Essentially, the mice were cured of haemophilia by editing the genome of their liver cells to correct the defective gene.

Could this help with HD?

It hasn't escaped anyone's attention that *genome editing* technology could be very powerful for Huntington's disease.

Because HD is always caused by an expansion of the same C-A-G tract in the same genetic location, it's possible to imagine using *genome editing* to remove some of those "extra" CAGs. In effect, this would cut the mutation right out of a cell's DNA.

There are a couple of problems that will need to be overcome before it becomes a reality. In the haemophilia mice, a healthy gene was added without removing the defective gene. That wouldn't work in HD because it's a toxic protein, not a missing protein, that causes the problems. So the technique will need to be modified to snip out the harmful CAGs, or deactivate the mutant gene, instead.

In addition, it will be more difficult to get the zinc finger nuclease treatment into brain cells than into liver cells.

Excitingly, though, genome editing research has already begun in Huntington's disease. CHDI, the leading organization funding HD research world-wide, has set up an HD genome editing program.

In a blog post, CHDI vice-president Ignacio Munoz-Sanjuan said, "After more than 2 years of trying, Sangamo and CHDI are now partners. Let's never give up having 'science fiction' dreams — one never knows how far science and technology will take humanity."

It will take several years before genome editing can be retooled to work in the brain of Huntington's disease patients — but this positive result represents a new avenue of research with great potential.

Acknowledgement: http://hdBuzz.net

Auckland / Northland News

HD Auckland's annual conference

It's been a rollercoaster year for the Auckland HD group, and this was highlighted to great effect at the annual conference. Held on Saturday 9th July, the conference and Annual General Meeting featured around 50 members from across Northland, Auckland and Waikato.

It was the final AGM for treasurer and former Chairman Richard Price. The tough economic times have created funding difficulties for many charities, including HD Auckland. Five traditional funders did not provide any grants to the association in the past year, and several others reduced the level of previous support. Richard has risen to the challenge. Over the past year through researching new funding channels and improving our applications and accountability tracking we have increased funding in very trying times. The Association was able to more than replace the lost funding streams, which allowed us to continue and increase the support provided to those in our community. Our new treasurer Trevor Lowe has now taken over the reins of sourcing funding.

Richard Price, the former Association treasurer, presenting the annual financial report

We also knew we needed to work to secure funding from alternative sources than grants to ensure our long term viability. A significant driver of this, providing a huge boost to fundraising has been new committee member Leanne Knox. Through a charity dinner last year, Leanne raised over $32,000 which was shared with the Waikato support team. For us this has meant the provision of a second vehicle for the Family Liaison team Jo Dysart and Jane Devine. It has also allowed us to appoint a part-time paid administrator. This growth in our ability to support members and the community will have a significant impact in the current year.

Family Liaison Coordinators Jo Dysart and Jane Devine were presented with gifts for all their hard work over the past year.

In the year to March 2011, largely due to funding constraints we attempted to reduce maintenance visits with clients. This had a negative effect on the increased need for subsequent interventions and support and is not something we would wish to repeat. The team made 4,159 home visits (down from 4,312 in the previous year) and received 12,001 phone call support enquiries (up from 7,534).

In her presentation to the Association, Jo described some very exciting research indicating how important the HD Association is for keeping families well. This shows that the service provided by Jo and Jane is keeping people out of hospital, which means that people living with HD can keep well for longer living at home. Jo and Jane will be heading to Melbourne in September to present this and other exciting research at the HD World Congress. There they will mix with top scientists and health carers from around the world to share the latest information on HD care.

New administrator

HD Auckland is very proud to introduce our new administrator Debra Hart. Debra has joined the association to manage the HD office by taking phone calls, helping with accounts, events, fundraising activity and applications, and general administration. This role also shifts much of the day to day workload of administration into the Association thereby reducing the impact on the Committee volunteers. We are hopeful of adding new committee members to our team when the workload is more manageable.

Chairman Mark Dunlop and neurologist Dr Richard Roxburgh presenting at the conference.

Continues on page seven

Continued from page six

Latest HD research information

Professor Richard Faull and his research team from the Centre for Brain Research at The University of Auckland also joined the conference to present their latest findings. The team described the work undertaken across the Centre, from biomedical science to psychological research.

Professor Richard Faull with PhD student Pritika Narayan and Dr Thomas Park from the Centre for Brain Research.

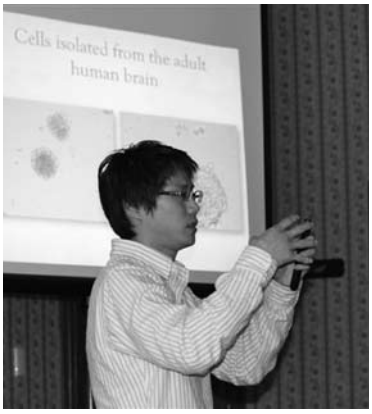
CREST-E

Dr Richard Roxburgh, who is part of the Centre and also a neurologist at Auckland District Health Board, joined the conference to talk about the 'CREST-E' study currently underway. The clinical team is recruiting participants for this three year study, which is a rigorous look at whether the nutritional supplement creatine can help brain function in HD.

Neurologist Dr Richard Roxburgh presenting on the CREST-E creatine trial.

Professor Richard Faull presented the latest from his team at the Centre for Brain Research.

Stem cells



Dr Thomas Park from the Centre for Brain Research.

Research Fellow Dr Thomas Park described his work on stem cells in the human brain. Thomas has recently been awarded a PhD for his research on growing and studying neural stem cells. These cells are found in the human brain, and could potentially be used in the future to repair diseased tissue. Thomas did his research using tissue from the Human Brain Bank, and is now looking at developing drug treatments to keep these cells alive.

He says; "We are so grateful to all the families who donate a loved one's brain to science. Without these precious gifts we couldn't do this research."

Environment and epigenetics

PhD student Pritika Narayan from the Centre for Brain Research.

Pritika Narayan described her PhD project examining the 'epigenetics' of HD symptoms. While HD is a genetic disease, many environmental factors can influence its progression and symptoms. Epigenetics describes how these environmental factors – like diet, toxins and other genes – relate to our DNA, and can influence the expression of the HD gene. In the future it is hoped that epigenetic research may mean we have more information about how to influence the environment of a disease – meaning that patients can learn how to keep healthier for longer.

You can find all the latest news, events and information on our website, as well as opportunities to help us. The presentation from the AGM is also online. Check it out! http://www.hdauckland.org.nz/

Wellington News

(Covering the following Wellington Huntington's Disease Association areas *Hawkes Bay, Taranaki, Wanganui, Wellington, Wairarapa and Gisborne).*

Greater Wellington

Hello everyone,

It has been a busy few months for me in the greater Wellington area. I participated again in Brain Awareness Week and had a stand at Brain Day at Rutherford House. Each year, the public participation improves and although there was not any HD specific lectures, it is a valuable way of disseminating information and the Neurological Foundation do a great deal to publicise it.

I am fortunate to be able to attend the World Huntington's Congress in Melbourne in September, which I am sure will be a most interesting conference. I am grateful to the Neurological Foundation for their approval of my funding application and I am looking forward to joining with Hilly Lutter, the Service Manager at Amaryllis House who is also attending. I am sure we will have plenty of information to share on our return.

Our swimming group at the Hutt Hospital hydrotherapy pool continues and we now have a community volunteer to assist which means that an extra client can join the group.

I recently joined with staff and residents of Amaryllis in taking clients to a show of Operatunity, a group of singers who perform regularly throughout New Zealand with day time concerts followed by lunch. The theme this time was Viva La France and the show was very much enjoyed by us all.

A number of clients have been hospitalised over the past couple of months for various illnesses. This is a stressful time for families and I hope I can offer support in these circumstances.

This year, I commenced study in an on line programme from UCOL called post graduate Human Clinical Genetics. Fortunately, I have passed the exam for the first semester and am about to start the second paper. It is a new programme this year but is very interesting and relevant to my work.

I hope families are keeping warm and well now that winter seems to have hit after the long autumn.

I continue to visit as possible but as always, should anyone require specific assistance, please phone, text or email me.

Regards

Jeanette Wiggins

Taranaki, Wanganui and Palmerston North

Unfortunately, Fleur Brett resigned her position as Huntington's Advisor (Taranaki, Whanganui and Palmerston North) due to family circumstances meaning that she moved out of the area. We thank her for her contribution.

The Association welcomes Karen Evans NZRN who has very recently started as the new Advisor. We wish her well in this valuable position.

Kia Ora everyone,

My name is Karen Evans. I have been living in Palmerston North for over 20yrs after moving down with my family from Cambridge. I am married and we have two adult daughters (living in Manawatu & Waikato). I grew up on a dairy farm on the coast of South Taranaki.

My working background has been in support work in both health and education. Healthcare became my main focus however and I'm a Registered Nurse.

Other interests I have include photography, reading, poetry, music, gardens and exercise.

I look forward to meeting everybody in the Manawatu/Wanganui/Taranaki regions in the near future.

I can be contacted on (06) 213 0307 or (027) 496 6500.

My email address is kevans.wellingtonhda@hotmail.com or you may write to me C/- PO Box 30420, Lower Hutt 5040

Kind regards

Karen

Continues on page nine

Continued from page eight

Hawkes Bay News

Kia ora koutou. Hello everyone. Winter has arrived! Hope you are all looking after each other and keeping warm.

Here in Hawkes Bay we had a cosy Winter Get-Together with a shared lunch, and Jo our Massage Therapist provided relaxing foot massages.

Don't worry if you missed out - our Spring Get-Together in September will be another opportunity to get together and share food, laughter, and some treats.

My main role is to support families. Everyone is unique in their needs around HD, whether they are the person with HD, or a carer, or a family member. I aim to support each family and each person within that family in the way that they wish and in the way that will have the best impact and outcome for them.

I met with the Neurological Foundation worker and a number of other community workers and we are putting together a joint extravaganza of fun and information for Brain Awareness Week 2012. Watch This Space!

If anyone would like to contact me for information and support for themselves or their family, or their workplace, please do not hesitate to do so, either via the phone or the email. I would love to hear from you.

Kia kaha. Keep Strong

Tanya Jeffcoat

ph (06) 8353020

Christchurch News

Greetings from Christchurch…. Well the days are shorter and the mornings are colder, this usually means that we have a nice day and we certainly need something on our side at the moment.

Christchurch has under gone huge upheaval and uncertainty for all of us. Meeting venues are no longer available on one side of the town and people are feeling very fragile about going out at night and wanting to stay near loved ones because of the knowledge that aftershocks can and do strike at any time.

Our association is in very good hands with our local DHB extending the role that Maggie Jury does of Clinical Co-Coordinator for people with HD, for a further three months before it reviews it again, this will hopefully be continued as the benefits to our HD families are huge.

I do not think our association has ever been so settled, because of the intervention and work that Maggie does in conjunction with health professionals and our Liaison Worker, Anne Wilson. We do not get families or our HD people in crisis before suitable invention is put in place. Everyone's needs are assessed on a regular basis with Maggie picking up on things starting to go wrong well before they do and putting strategies or support in place to avert this. Even through all the uncertainty of the last nine months our HD people are all coping very well. So a big thank you to Maggie and Anne for all the work and support that you give our families.

The new HD service that has been doomed with many different opening dates is still unable to open its doors to our HD loved ones. The house has now got water back on but is still on a temporary sewerage system. The NZCare clients that are currently residing there are still unable to return to their homes due to further damage from our June earthquakes. This is a very frustrating time for both NZCare and our association as we wait out the waiting game. Nothing is moving very fast at the moment and for every three steps forward it seems to be two steps back. The reluctance to have any major work under taken is huge considering the amount of work that has been undone by the continual aftershocks.

I have included some photos of the new house for you all to see that it is there but just out of our reach at the moment.

Continues on page ten

Continued from page nine

Good news is that the two new Respite units are nearly completed on the same site as the house. These have not been held up due to them being a new build and builders contracted to start before the February earthquake. I am sure once we are up and running that these will get plenty of use.

We held our AGM in May and had a very good turnout. Graham Barnett from NZCare was our guest speaker and he brought along photos of the house to give us all a chance to see through it. This was an ideal time for questions and answers and reassured everyone that it will happen. We even got to see a photo of the 11 TV's that the association have purchased for the house that are all still sitting in there boxes waiting to be installed.

Maggie also talked to us about her role and the feedback from the many families that she deals with. This was very informative and the vastness of her weekly role was amazing to what she packs into a 20 hour week. Maggie is very passionate about HD and is a very good advocate out in the community for whatever she can achieve for her clients. Maggie and Anne work together closely and the two roles seem to cross over nicely.

We are very fortunate to have this position available to our families and will be very disheartened if it does not carry on.

On a personal note, we are all holding up well, the daily changes within the HD walk are always challenging but it is those precious moments, when our daughter Kimberley reminds us that she is still with us, that sense of humor is still there and her wicked love of teasing people comes out every now and then. It is these moments that we cherish and love, it is these moments in time that help on this journey.

Stay safe everyone

Dianne Collins

Chairperson HD Christchurch

Huntingtons Trust Wellington and Central North Island

The above Trust was set up in 1993. The aim was to get enough funds to enable it to help with the day to day running of the Wellington Association and/or specific projects.

Bequests to this Trust can be made in cash, shares, real estate, or any other property and can be by way of a gift during your lifetime or can be bequeathed in your will. Bequests are free from estate duty.

If you require further information please write to:

The Chairperson of the Trust,
P O Box 30420,
Lower Hutt 5040

Mailing List

To help us keep the mailing list as up to date as possible, could you please remember to drop us a note when you change your address. Include the name or names you want on the envelope plus your old address and new address.

If there are any mistakes that need updating, or a family member who received the newsletter has died, please let us know about them also.

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Huntington's News is the national Newsletter of the Huntington's Disease Associations of New Zealand. It is published quarterly (March, June, September, December) as a means of communication between the Associations and all individuals with Huntington's Disease, their families, their caregivers and professionals interested in the condition.

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Many thanks to all who continue to make private donations to our Association.

Contributions

Write to us about this newsletter, about information you may need, about information you may want to pass onto others. Write to us about controversial topics such as privacy, confidentiality, access, support, etc…

We would like to hear from you.

The next issue of Huntington's News will be published in December 2011. The deadline for material to be received for this issue will be 10 November 2011. Please send any contributions for Huntington's News to:

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IMPORTANT NOTICE:

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Please note that any article published in Huntington's News may be selected for reproduction on the INTERNET on the "Huntington's Disease Scene in New Zealand" website www.huntingtons.org.nz
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